

Meeting Minutes Texas Council on Alzheimer's Disease and Related Disorders Meeting Minutes – February 19, 2014 JJ Pickle Commons Learning Center 10100 Burnet Road Austin, Texas 78758

The Texas Council on Alzheimer's Disease and Related Disorders met on Wednesday, February 19, 2014, at the JJ Pickle Commons Learning Center, 10100 Burnet Road, Austin, Texas 78758

Council Members Present

The Honorable Clint Hackney, Vice-Chair Bonnie Curington, PhD, DSHS

Grayson R. Hankins

Susan Rountree, MD

Ronald DeVere, MD

Melissa L. Edwards

Lisa B. Glenn, MD

Deborah S. Hanna, Chair

Rita Hortenstine

Patty Moore, PhD

Robert Vogel, MD

Laura DeFina, MD

Council Members Absent

Carlos Escobar, MD Kate Allen Stukenberg Ray Lewis, DO

Guests Present

Paula Grammas, PhD, Texas Tech HSC

George Perry, PhD, UTSA

Diana Kerwin, MD

Katie Wiechnicki, DSHS - HPCDP

Marcelo Kort, Lilly

Lisa Glass, Ross Communications

Beth Lynn Maxwell, UT System

James Crowson, Attorney General's Office

Denise Rose, TAMHSC

Janice Knebl, UNTHSC

Danny Jensen, UNTHSC

Thomas Fairchild, UNTHSC

Nancy Turco, Alzheimer's volunteer

Staff Members Present

Lynda Taylor, DSHS - HPCDP

1. Welcome/Call to Order/Roll Call/Excuse Absent Members

Ms. Debbie Hanna called the meeting to order at 8:35 am. Ms. Lynda Taylor certified roll, and a quorum was present. Members, guests and new members were welcomed and introduced.

Dr. Carlos Escobar and Ms. Kate Allen Stukenberg extended their apologies for not attending. Dr. Ray Lewis was also absent. Ms. Hanna requested that the absence of Dr. Escobar, Ms. Stukenberg and Dr. Lewis be excused. The Honorable Clint Hackney moved for the excused absence. Grayson R. Hankins seconded the motion. All were in favor.

2. Approval of Council Minutes from the August 28, 2013, Meeting

Ms. Hanna asked Council members to review the minutes from the August 28, 2013, meeting. Dr. Ron DeVere moved that the minutes be approved as presented. Ms. Melissa Edwards seconded the motion. All were in favor, and the August 28, 2013, meeting minutes were approved as presented.

3. DSHS Staff Changes

Ms. Hanna announced that Ms. Susan Ristine, the previous DSHS Alzheimer's Disease Program Coordinator had retired. Ms. Lynda Taylor was hired in November 2013 as the new Coordinator.

4. TARCC Consortium Director Introduction: Paula Grammas, PhD

Ms. Hanna introduced Paula Grammas, PhD, as the Consortium Director for the Texas Alzheimer's Research and Care Consortium (TARCC). Dr. Grammas reports directly to the Council.

The Texas Council on Alzheimer's Disease and Related Disorders (the Council) identified the need for permanent supervision of TARCC in order to expand its reach in developing programs and research. The Council conducted a search for a director in the summer of 2013.

Dr. Grammas comes to TARCC from the Texas Tech University Health Sciences Center, School of Medicine, where she served as the Executive Director of the Garrison Institute on Aging, Mildred and Shirley L. Garrison Chair in Aging, and Professor of Neurology. Previously, Dr. Grammas was the director of the Oklahoma Center for Neuroscience at the University of Oklahoma Health Sciences Center, the Presbyterian Health Foundation Endowed Chair in Neuroscience, and adjunct professor of cell biology, geriatrics, psychology and behavioral science at the University of Oklahoma Health Sciences Center. Dr. Grammas is originally from Long Island, NY.

The first TARCC Steering Committee meeting of the year will be on February 20, 2014.

5. Update on TARCC Activities

Dr. Grammas provided an overview of the current TARCC activities and the possibilities for expanding TARCC's reach. A priority is the promotion of statewide collaborations to include non-

TARCC institutions and younger researchers. There is a need to translate basic science research in order to "take research to the bedside." This investment in effort will create a bigger base for what TARCC wants to accomplish. More discussions are needed to determine where TARCC wants to be. The TARCC Steering Committee meeting will continue this discussion on February 20, 2014.

Dr. Grammas provided an update on the Texas Harris Alzheimer's Research Study.

6. Texas A&M Health Science Center Program and Research Initiative

Ms. Hanna introduced the Investigator Outreach Program in draft form as authored by Dr. Grammas and handed out a program concept paper. This program will be administered by Texas A&M University (TAMU). TAMU researchers are currently involved in TARCC activities. The goal is to develop a scientific core to be more prepared to participate in existing activities of TARCC that eventually will connect TARCC with public health efforts. Funds for 10 2-year grants will be awarded to equal \$1,250,000. It is important to note that TAMU does not receive these funds for their own use but will manage the grant program that distributes these monies to colleges, universities and medical schools across Texas to conduct Alzheimer's research utilizing, to the maximum extent possible, the TARCC cohort.

Dr. Grammas described the program as a way to jumpstart research collaboration to further the understanding of Alzheimer's disease in many ways:

- 1. Provide opportunities for faculty
- 2. Foster involvement of younger faculty
- 3. Involve clinical & basic faculty
 - a. Statewide reach of A&M (network and experience)
 - b. Lots of effort for dissemination
- 4. Encourage dialogue on scientific research on AD
- 5. Prepare for a public approach down the road

Ms. Hanna stated that TAMU is accepting a big responsibility. TARCC has full support from the scientific community at A&M. This is a good first step in leveraging the strengths of TAMU and addressing a real need. The program will be open to researchers around the state who can utilize the cohort for their research.

Ms. Hanna asked for a motion to adopt the expenditure for the Texas A&M Health Science Center Investigator Outreach Program. The Honorable Clint Hackney moved to adopt this expenditure. Grayson R. Hankins seconded the motion. All were in favor, and the motion passed unanimously. A memorandum of understanding will be drafted by the summer.

Dr. Grammas thanked the Council.

7. External Advisory Committee Update

Dr. Grammas will work with the External Advisory Committee. Ron Petersen, MD, PhD, of Mayo Clinic serves as chair of this group of 5 distinguished scientists from across the US who come together every other year to evaluate the activities of TARCC. Meetings are conducted in person and by conference calls. Dr. Grammas and Dr. Petersen will establish time and location for the review meeting. The Council will receive a written report of the findings in the late fall.

8. Consideration and possible action with respect to Memorandum of Understanding distributing funds to TARCC member sites & TARCC Contract Update

Ms. Hanna provided an overview of the TARCC contractual activities over the past year. The agreements with the TARCC schools are actually memorandums of understanding (MOU). At the August 28, 2013, Council meeting, the Council received information on the costs for TARCC and the patient cohort for the period September 1, 2013, through August 31, 2015. James Crowson of the Attorney General's Office prepared the MOUs. The 2013 MOUs were sent to the schools and included only changes in dates and dollar amounts. The MOUs were the same in content as has been signed by the schools since first funding in 2005. A discussion resulted within the six schools regarding the Intellectual Property sections of Exhibit E. Five of the six TARCC schools came to an understanding regarding the objectionable sections, signed the MOUs and accepted the funds.

Following weeks of negotiation, The University of North Texas Health Science Center (UNTHSC) declined to sign the MOU. The standards of compromise were negotiated by attorney Beth Lynn Maxwell of the University of Texas System. Pursuant to an email dated February 7, 2014, from S. Michelle Williams, Associate General Counsel University of North Texas System, UNTHSC is withdrawing from TARCC effective September 1, 2013. This is binding on the Council, and the Council accepted the withdrawal, as stated by Ms. Hanna, with great regret. Ms. Hanna asked that the record reflect the Council is very proud of the work of UNTHSC and Dr. Sid O'Bryant, formerly of Texas Tech HSC but most recently associated with UNTHSC. UNTHSC, TARCC, and the Council will work on an agreeable transition.

Ms. Hanna asked for questions:

Dr. Vogel: Why did UNTHSC withdraw?

Ms. Hanna: There was a disagreement over language and the process for working it out. Five of

the six member schools and their attorneys came to an agreement with the

attorneys for UT System and the Attorney General's office.

Dr. Vogel: Will we lose Sid O'Bryant? He has done much to advance the science.

Ms. Hanna: I hope this is not final.

Mr. Hackney: Can they come back at a later time?

Ms. Hanna: They are part of our research family by statute. I am not even sure they can resign.

I know they can choose to not participate. Please be very clear, the email I

distributed indicates they resigned and it came as a shock. We never asked them to leave. We hope that the disagreements can be worked out.

Mr. Crowson: UNTHSC could/would not continue with the language as it was written. They could

be included in the future. It is a matter of working out the details.

Ms. Maxwell: The process clarified ideas.

Dr. Fairchild: (Steering Committee of UNTHSC)

Based on the regent's rules, they are not allowed to give away intellectual property. The withdrawal related only through the balance of this fiscal year. No funds were received for the new fiscal year. UNTHSC will continue to be active on the TARCC

steering committee during this time.

Mr. Hackney: We should do something to get UNTHSC back in.

Ms. Maxwell: Campuses that work well together are committed to research and know that there

are other things to continue working together on.

Ms. Hanna: Do you know why the resignation from UNTHSC was effective retroactively back to

September 1, 2013?

Mr. Crowson: I do not.

Mr. Crowson: Intellectual property matters can be worked out. This is a disappointment.

9. Time and Date for Next Council Meeting

Ms. Hanna explained that if needed she would call an emergency meeting of the Council. The next planned meeting of the Council will occur in the fall of 2014.

10. Public Comment

There was no public comment.

11. Adjourn

There being no further business, the meeting was adjourned at 9:30 am.